

Dominant

Beatriz De Faria Sousa, BS

AUTHOR AFFILIATION:

Florida International University
Herbert Wertheim College of
Medicine Miami, FL

CORRESPONDING AUTHOR:

Beatriz De Faria Sousa, Florida
International University Herbert
Wertheim College of Medicine
Miami, FL,
bdefa004@fiu.edu

HOW TO CITE: De Faria Sousa B.
Dominant. *Fam Med.* 2026;0(0):1–2.
doi: [10.22454/FamMed.2026.934059](https://doi.org/10.22454/FamMed.2026.934059)

FIRST PUBLISHED: July 15, 2026

© Society of Teachers of Family
Medicine

At 42, after a series of small strokes and the name they finally gave them – CADASIL – I began to lose hold of ordinary life. A job I once did easily became a forest of errors. The simple turned elusive: numbers blurred, sleep came unannounced, words tangled before leaving my mouth. This illness moves through families, quiet but certain. It is dominant, the neurologist said, and with that adjective a question arrived and lingered: should I tell my children what might be coming for them? Is knowledge a gift, or a sentence? I have yet to reach a verdict.

They called the first one “a transient episode,” which sounded like an apology wrapped in a euphemism, as if my body had briefly stepped out and would soon return. I remember the numbers loosening, slipping from their rows, my hand hovering above the keyboard without command. The moment was brief, seconds, maybe a minute, but something essential went dark. My first “mini stroke,” they called it later. When the neurologist traced the ghostly constellations on my MRI, he said *lacunes*, tiny lakes of damage in the white matter. It was almost pretty on the screen, until I remembered it was me.

I did not cry. I listened.

He said, “Cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy,” a phrase long enough to wrap the room.

I repeated the acronym like a foreign word: “CA-DA-SIL.” I wondered what it meant in days.

I tried, for a while, to hold myself together. I made lists, then lists of the lists, and set alarms to remind me of the others. The headaches came sudden, uninvited, impossible to ignore. I felt heavy and hollow at once, as if someone had filled me with fog. I made mistakes that didn’t feel like mine: names misplaced, thoughts dissolving midsentence. It would be easy to be angry if I didn’t keep forgetting why.

When my memory begins to loosen, it is not facts I fear losing, but faces. The first are my children. Two of them, each carrying some small proof that I was here. I only hope their memories of me last longer than my own.

My eldest daughter has my eyes and temper. When their father died, she couldn’t bear the silence that followed. Grief needed somewhere to land, and I was close enough to take the hit. The youngest still lives close to me. He just started college, and wants to be a screenwriter, make sense of chaos by giving it dialogue. I listen, proud and afraid. I wonder if his mind will stay his long enough to live, to love, to write the story already forming in him.

Sometimes, watching them, I almost believe the future is still negotiable, that some quiet grace might spare them. But then I remember. “Fifty percent,” the neurologist said. A coin tossed into the dark.

Should I tell them? Should I change the shape of their lives with knowledge they cannot return? What kind of mother holds a secret that might spare her children, or ruin their peace?

My eldest would blame me, I think. She could not forgive me for failing to save her father, and now I am offering her another grief wrapped in science. If I tell them, I give them agency, and the waiting that comes with it. If I keep silent, I give them ignorance, and the innocence that ignorance allows. Which is kinder? To open the door to dread, or to lock it and stand guard on the other side?

If they are tested, maybe one could be spared. Freedom written in their blood like a benediction. The other might not be so lucky. What will that do to them? To sit at the

same table, knowing that one carries a countdown the other escaped? It feels like Sophie's choice without the choosing, a cruelty delegated to chance. And yet silence feels no kinder.

Sometimes I wonder if knowing earlier would have changed anything for me. Would I have had children, built a life around the quiet countdown of my own genes? Or would I have lived louder, more urgently, before the fog arrived? What is the ethical thing to do—to warn them, or to let them believe that their futures are still theirs to write?

This is not only a medical question. It is an ethical hinge disguised as a family conversation, the kind that eventually finds its way into a clinic room, where certainty is scarce and the weight of knowing must be shared. It is an invitation to deliver a future as if it were a gift, when it may be a weight. How to tell the truth without making it heavier than it already is, how to counsel a family when medicine offers probabilities but not peace? To know is to organize your fear; to not know is to be surprised by it.

Perhaps every parent lives inside a small, merciful dishonesty: the wish to protect our children from the future while knowing we cannot. I have come to recognize it in clinical spaces as well—the careful way difficult truths are offered, softened at the edges, carried just gently enough that they might be received. We all practice this quiet deceit in gentler ways—admiring dresses we do not like, offering hope we can't quite hold ourselves, promising that everything will be all right. Not to deceive, but to delay the shadow crossing a beloved face.

There is so much I mean to say, but the sentences unravel before they reach the air. I am tired. *Exhausted*. Of waiting, choosing, balancing silence and love in the same unsteady hand.

The days bleed forward, indistinguishable. The youngest watches me closely now; my eldest calls between errands, worried. They do not yet know what might sleep inside them. They only know that I am slowly fading. I keep meaning to tell them. I keep meaning to do so many things.

I suppose we all do.